



Volume 17  
Issue 2  
2023

## The Silenced Side of Living Donation Evaluating the Measures of Success in Living Organ Donation

*Alisha Hiebert*

I am the oldest of four in a family forged through adoption. Growing up my siblings and I experienced a typical relationship that could be summed up with the sentiment, “I’d give up an organ for you but don’t touch the TV remote.”

I am the only one in my family with Glycogen Storage Disease, the genetic condition hallmarked by the cruel inability to convert glycogen into glucose, and the very thing that resulted in my need for a transplant. When the time came that a new liver seemed like the best viable option, my doctors recommended we first look at living donors. Both of my parents eagerly hopped in line to get tested, and due to various circumstances, neither was a match. More donors, not related, were tested on my behalf, each one denied. The longer I waited, the more my body deteriorated, and my condition worsened. My biological brother, who was in college at the time, came forward and offered to get tested. I was in the parking lot of the hardware store when my phone rang, the transplant coordinator confirming what I already knew in my bones to be true. He was an ideal match, and our shared surgery date was scheduled for the middle of August.

I was concerned for my own survival, but my big sister instincts also kicked in and I was equally concerned for him. He was young, physically fit,

an ideal candidate in every medical sense. It was these very things that made me nervous. I knew if something happened to him, the guilt would eat me alive. Leading up to the surgery, my medical team reiterated the risks until the numbers were almost meaningless. Their reassurances were little comfort: they wouldn't do the surgery if they didn't feel it was safe; if my body rejected the organ, my brother wouldn't be to blame; I wasn't to blame if something went wrong in his surgery. He was four years younger than me. Even if there was no talking him out of it, it had always been my job to protect him. Now here he was, undergoing major surgery because of me.

The morning of our surgeries, he went into the operating room before me. A few hours after his surgery had already begun and before mine was scheduled to commence, I was taken back to pre-op, to wait among the rows of stretchers bearing people waiting to be moved into the operating theatres. Huge double doors led to the outer part of the hospital where our family waited. Every time the doors separating the OR waiting area and the rest of the hospital swung open, despite knowing his body already boasted the mark of a surgeon's scalpel, I hoped to see him. I was alone for this part, and so was he, but I wanted to be alone together. We were about to embark on a journey no one else would ever understand, and all I wanted was his hand to hold along the way.

The surgery did not go according to plan. I would learn later, from perusing medical records and asking doctors who flocked to my bedside to marvel at this medical unravelling, that in the

middle of my surgery, my brother had unexpected complications. Surgeons hopped from one room to the next, trying to stabilize both of us. I hadn't even left the OR for the first time when doctors were already speculating that I would need a second transplant. In the days I spent sedated, intubated, fighting for my life, my brother was fighting for his, in his own way. My parents entered every parent's worst nightmare, crossing the hallways of the ICU, going from the bedside of their son to the bedside of their daughter.

Before my eyes even opened, I knew. I knew the liver inside my body didn't belong to my brother. It was unfamiliar and not at all familial. When the words were finally spoken, when my mother told me that I had received a second transplant, she led with the words "Jacob is fine."

In that moment, I would have traded the entire world to make sure he was ok. My own survival was secondary; the need to make sure he was alright pervasive. Jacob—the baby I used to dress up, the child who I pushed down the stairs for playing with my toys, the one who grew up and became this funny, wise man I consider one of my best friends—an entire life flashed before my eyes. It wasn't mine, but his.

Due to hospital regulations during Covid-19, the first time I was able to see him was weeks later, when I was finally released from the hospital. As I crossed the street towards my rented apartment across from the transplant centre, I saw my brother and began sobbing. There are no words for the way I exhaled when I finally saw that he was safe.

It has been two years since both of our lives changed forever. My second transplant from a deceased donor is considered successful thus far, and my brother is studying abroad for his final year of college. In terms of statistics, we are a mostly successful story.

Except there are nights when I can't sleep, when the only thing I can feel is intense guilt for what I put him through. The flashbacks of what it cost to survive are so vivid they threaten to steal the air from my lungs. And I know he'd do it all again. I can't help but think, though, that we can no longer quantify success as the sheer survival of two people. We both live with trauma and scars that won't go away, haunted by what ifs and what should have been. We are the side of living donation that isn't talked about.

When it gets quiet, when the calendar pages turn to August and I walk the familiar hospital hallways, when I think of this transplant journey and the places it has taken me, I think of him. Not for giving me part of his liver, but for the ways in which we walked through hell. The bond we share is one no one will ever understand, and if I had to go there with anyone, I'm really glad it was with him.

Hey J, I love you. Forever and always, your big sister.

### **About the Author**

**Alisha Hiebert**, a two-time transplant recipient, is a writer, grief coach, and patient advocate living in Alberta, Canada. Instagram: @thealiemerald Email: ahiebert@live.com